

...offering
information and
inspiration to
individuals with
disabilities and
their families as
they direct their
own supports and
services



Volume 2, Number 3
March 2004

What I Would Want My Job Coach to Know and Do

by Michael W. Smull

Listening to a gathering of job coaches in Wisconsin I began to think of all of the things that people with disabilities have taught me about what they want their job coach to know and what they want their job coach to do. Some of what follows I learned from 10 years as a community service provider, much of it I learned from listening as I have been doing person centered planning with people from all over North America. The following list of requests represents a summary of what I have been told - with words and behavior.

Understand how I want to live.

I know that you are only responsible for helping me with work, but what I do for work has to fit with how I want to live. Please do not divide my life into compartments. Listen to what I say about the rest of life. If I cannot speak for myself, talk to the people who support me where I live. If I am moving to a community job from a workshop or day program, remember that I may be leaving all my friends and someone needs to help me stay in touch with them.

**“ . . . please do not
divide my life into
compartments.
Listen to what I
say about the rest
of my life . . . ”**

Understand the role of work in my life.

What work means to me may be different from what work means to you. Work may be how I get status, it may define who I am. What I do may be more important than how much I earn. Alternatively, work may be what I do so that I can afford what I enjoy. Or the role of work may be some mix of status and income. Regardless of whether or not I can put this into words, you need to make an effort to understand the role of work in my life.

Learn about my dreams/desires, gifts and capacities.

You need to know what I am good at in order to find me a job where I can be successful. You also need to find out what my "fantasy" or perfect job would be. The job that I would really like may not be where I score the highest on your assessments. Help me get a job that I want. If the "perfect job" is beyond my grasp see how close you can help me get.

Person-Centered Work Principles:

5 Accomplishments

by John O'Brian and Connie Lyle

Community presence: the sharing of the ordinary places that define community life. - What community settings does the person use regularly (daily, weekly occasionally)? - To which of these places does the person go alone? as part of a group of two or three? as part of a larger group? - Does the person have any significant problem using any of these places?

What other community settings would it be in the person's best interest to use, or to use more independently? What would it take to increase the number of community settings the person uses completely? (Consider changes in the person's skills, changes in available assistance, negotiating changes in the setting or changes in service patterns.)

Choice: the experience of autonomy both in small, everyday matters (e.g., what to eat or what to wear) and in large, life-defining matters (e.g., with whom to live or what sort of work to do). - What decisions are regularly made by the person? - What decisions are made for the person by others? For which of these could decision making be transferred to the person himself or herself? - What are the person's strongest interests and preferences that make him or her unique? - What would it take to increase the number, variety, and importance of the decisions the person makes? What would it take to increase other's knowledge of the person's interests and preferences?

Competence: the opportunity to perform functional and meaningful activities with whatever level or type of assistance is required. - What skills could the person develop that would offer the most opportunity for increased presence, choice, respect, and participation? - What strategies for instruction and assistance have been most effective for the person? - Are there more efficient strategies than instruction, such as environmental modification or provision of additional personal assistance? Are there any health-related threats to the

person's continuing development? How can these be managed effectively with minimal disruption of good quality life experiences? - What would it take to increase the person's competence in more valued activities?

Respect: having a valued place among a network of people and valued roles in community life. - What are the valued community roles the person occupies and what percentage of time is spent in each? - Which community roles offer the person the best opportunity to express individual gifts and talents? -- What would it take to increase the amount of time the person spends in a valued community role? * What images and ideas about a desirable future are available to the person? Does the person display any characteristics that reinforce stereotyped perceptions of people with severe handicaps? - Are there any characteristics of the person's environment that reinforce stereotyped perceptions of people with severe handicaps? (Consider the images projected by activities, schedules, expectations, and the way the person is spoken to and about.) What would it take to decrease the stigma the person experiences?

Community participation: the experience of being part of a growing network of personal relationships that include close friends. - With whom does the person spend the most time on a daily and weekly basis? How many of these people are other clients/students in the same program? How many are program staff? How many are people with apparent handicaps? - Are there other important people in the person's social network with whom the person spends time occasionally? - Who are the person's friends and allies? Who knows the person intimately? Who will act as an advocate for his or her interests? What would it take to provide better support for the person's present network of relationships? What would it take to develop more friends or allies? - What would it take to increase the number of non disabled people, including age-peers, who know and spend time with the person as an individual?

From Wilcox B. and Bellamy, G. T. (1987). A comprehensive guide to the activities catalog. Baltimore: Paul Brooksne of the most common mistakes made by people who are new to person-centered planning is the assumption that everyone has similar goals and values.

Do not "place" me, offer me a job that you think will make sense for me.

Even if it took you six months to develop a job, it ought to be OK for me to say no. Part of respecting me is respecting my decisions. At the same time, if I need encouragement to try something new, if saying no is my way of saying I am scared, encourage me but do not coerce me.

Do not try to make me "independent."

Help me learn the skills that I will need to do the job. Help my co-workers learn how I learn and how to support me. Help me get to know my co-workers and to have reciprocal relationships with them. The result for you may be that I am more independent of the system. The result I want is the interdependence that all of us have.

Help me become part of my work place.

Help my co-workers meet me (and get to know me) as a person rather than as a disability. Show them by your example. (They will learn more from how you treat me than they will from what you tell them.) Work on talking about me using respectful, people first language. Use language that empowers me. This will tell my co-workers that I am somebody that they should respect. Learn the culture and the "positive rituals" of the work place. Help me enter the culture and participate in the positive rituals. Remember that your planning meetings may not help me be seen as a co-worker.

Be there if I need help because of challenges in other parts of my life, or changes at work.

Things that happen at home may affect my work. If people leave my life (e.g., family members who move, are hospitalized, or die; residential staff who leave) I may

have problems doing my work. I will need support and understanding, I may need some time off and/or counseling. Remember that I may like my job because of who I work with. When people who are important to me leave my work place, be ready to help me.

Keep listening to my words (and behavior) for requests

"...Change should occur on my schedule, not on yours. I may not want to wait for my next planning meeting..."

for change - a change in responsibilities, supervision, pay, or where I work.

Just like any other worker, I may get tired of my routine. I may no longer find my job satisfying or enjoyable. I may want a raise. Because of how my co-workers and I relate to each other, I may need to change who I work with. I may want a complete change - in who I work for, what I do, and where I work. Changes like these require that you take into account the local job market, but please help me make the changes as I want them and when I want them. Change should occur on my schedule, not on yours. I may not want to wait for my next planning meeting.

Help me find new jobs as I want/need them.

This is important enough to mention twice. My experience is that if I complain about my job I get counseling. If I act out my unhappy feelings I get a behavior program. I can only get a new job by really screwing up the old job. Please help me build the kind of job history that you want to have. Let me build on success. Help me find new jobs as often (and as seldom) as I ask for them.

PLEASE ADD ME TO THE MAILING LIST:

Name _____

Address _____

City _____

State/Zip _____

Send to:
New Directions
CCS Communications
P.O. Box 384
Hopewell, NJ 08252

March 2004

new directions

is produced 10 times a year by CCS Communications under a contract for the New Jersey Council on Developmental Disabilities.

The views and opinions do not necessarily reflect those of the editor, the Division of Developmental Disabilities or the Council, its staff or its volunteer members.

Editor: Brenda Considine
CCS Communications
P.O. Box 384
Hopewell, NJ 08525

phone/fax: 609-466-0694
consid@comcast.net

Dear Editor:

I would like to clarify a point made in the article: Real Life Choices is Launched. The article explained that Real Life Choices is a win for the State because it will provide more federal matching funds under the Community Care Waiver (CCW), a Medicaid program. This statement implies that we do not receive those federal funds for more traditional services. For decades, NJ has not been maximizing its federal revenues from the CCW for all services to people with developmental disabilities. Governor McGreevey's Administration is the first to acknowledge this, and is now claiming for federal money for services to eligible individuals under the traditional group homes and day programs. In the current fiscal year, the State will receive \$22 million more in federal money than it received in the previous year for traditional programs. This year, the State is using \$9.8 million of those additional federal funds to expand services to approximately 300 individuals through Real Life Choices. Real Life Choices, like all Waiver services, will generate \$1 from the federal government for each \$1 spent by the State, a 50% match. The proposed FY 2005 budget assumes that the State will receive an additional \$15.7 million more from the federal government than it did in the current fiscal year. We need to ensure that all federal money claimed for under the Community Care Waiver, both from Real Life Choices and the more traditional programs, are re-invested in community services for people with developmental disabilities.

Lowell Arye, Executive Director

ABCD- Alliance for the Betterment of Citizens with Disabilities, Hamilton, NJ

new directions

New Jersey Developmental Disabilities Council
P.O. Box 700
Trenton, NJ 08625

FIRST CLASS U.S.

POSTAGE

PAID

Trenton, N.J. 086
PERMIT #21